Low Quality of Life and its Associated Risk Factors in Parents of Children with Cerebral Palsy in the Northwest of Iran; A Case Control Study

Kuzey Batı İran'da Serebral Felçli Çocukların Ebeveynlerinde Düşük Yaşam Kalitesi ve Buna Bağlı Risk Faktörleri, Bir Vaka Kontrol Çalışması

Quality of Life in Parents of CP Children

Mahnaz Hejazi Shirmard[1], Mahdieh Seyyedi[1], Vahideh Toopchizadeh[2], Morteza Ghojazadeh[3]
[1]Faculty of Rehabilitation, [2]Physical Medicine and Rehabilitation Research Center,
[3]Liver & Gastrointestinal Disease Research Center, Tabriz University of Medical Sciences, Tabriz, Iran

Öz

Amaç: Bir çocuğun serebral felci (CP) ile ebeveyni birden fazla zorluklarla ilişkilendirilmiştir. Bu çalışmada çocuklarımızın ebeveyni ve sağlıklı çocukların yaşam kalitelerini ve muhtemel risk faktörleri ile olan korelasyonlarını karşılaştırmayı amaçladık. Gereç ve Yöntem: Yaşları ve cinsiyete göre eşleştirilmiş 64 anababalı ve 64 ebeveynli anne babanın 64 çocuğu çalışmaya alındı. Araştırmacılar, aileleri Dünya Sağlık Örgütü Yaşam Kalitesi - kısa versiyonu (WHOQOL-BREF) ve Duke Üniversitesi Din Endeksi (DUREL) anababalarını ebeveynlere uygulamak için ziyaret ettiler. Ayrıca, Brüt Motor Fonksiyon Sınıflama Sistemine (GMFCS) göre çocukların motor fonksiyonları CP'li çocuklarda değerlendirildi. Bulgular: CP'li çocukların ebeveynleri, sağlıklı çocukların ebeveyni ile karşılaştırıldığında sosyal alt ölçeği dışındaki, dini inançları daha belirgin ve genel yaşam kalitesinde ve tüm alanlarında daha düşük puanlar aldı. Ebeveynlerin yaşı ile psikolojik alanı, sosyal etki alanı ve genel yaşam kalitesi arasında ve GMFCS düzeyi ile yaşam kalitesi ile sosyal ve çevresel etki arasında anlamlı negatif korelasyon vardı. Yüksek gelirli ailelerin sosyal, çevre sağlığı ve yaşam kalitesinde anlamlı derecede yüksek puanı vardı ve yüksek öğrenim görmüş ebeveynlerde çevre sağlığı daha yüksekti. Tartışma: CP'li çocukların ebeveynleri, çocukların özürlülüğünden, ebeveyn eğitiminden ve aile gelirlerinden olumsuz olarak etkilenen sağlıklı çocukların ailelerinden daha düşük yaşam kalitesine sahiptir. Her ne kadar bu ebeveynlerin dini inançları daha yüksek olsa da yaşam kalitesi alanlarıyla ilişkili değildir.

Anahtar Kelimeler

Serebral Palsi; Ebeveynler; Yaşam Kalitesi; Dini İnançlar

Abstract

Aim: Parenting a child with cerebral palsy (CP) presents multiple challenges. In this study we aim to compare the quality of life in parents of children with CP and parents of healthy children and its correlations with possible risk factors. Material and Method: Sixty-four parents of children with CP and 64 parents of healthy children matched for age and gender were recruited. Families were visited by researchers to administer the World Health Organization Quality of Life – short version (WHOQOL-BREF) and Duke University Religion Index (DUREL) questionnaires to parents. Also the motor function of the children with CP was evaluated according to the Gross Motor Function Classification System (GMFCS). Results: Compared to parents of healthy children, parents of children with CP had significantly stronger religious beliefs and a lower score in overall quality of life and all its domains, except for the social subscale. There was a significant negative correlation between parents' age and psychological domain, social domain, and overall quality of life. There was also a significant negative correlation between GMFCS level and the social and environmental health domains of quality of life. Families with higher income had a significantly higher score in social, environmental health, and overall quality of life, and environmental health was significantly higher in parents with higher education. Discussion: Parents of children with CP have lower quality of life than parents of healthy children; their quality of life was negatively correlated with their children's disability, their education level, and family income. Although these parents had stronger religious beliefs, this was not correlated with the domains of quality of life.

Keywords

Cerebral Palsy; Parents; Quality of Life; Religious Beliefs

DOI: 10.4328/JCAM.4939 Received: 01.02.2017 Accepted: 16.02.2017 Printed: 01.09.2017 J Clin Anal Med 2017;8(5): 431-5
Corresponding Author: Vahideh Toopchizadeh, Physical Medicine and Rehabilitation Research Center, Tabriz University of Medical Sciences, Tabriz, Iran.
T.: +984133373967; F.: +984133373967 E-Mail: toopchi.v@gmail.com

Introduction

Cerebral palsy (CP) is one of the most common developmental disabilities in childhood that persists throughout the lifespan. CP is a movement and posture disorder caused by non-progressive damage to the immature brain [1]. Children with CP have balance problems and poor social functioning and so are dependent on their parents [2,3].

Parenting a child with cerebral palsy presents multiple challenges. Caring for these children has a high psychosocial burden on the parents, including financial costs, detrimental effects on physical health, and reduced time for other relationships and activities [4]. Parents of children with CP compared to parents of children without disabilities usually show higher levels of stress and worse mental health [5,6].

It is possible that the burden of caring for a child with CP may influence the quality of life (QOL) of parents. Quality of life can be defined as the individual's personal perception of overall well-being and contentment in life, including both psychosocial and physical or health-related domains [7]. QOL of individuals can be affected by financial, physical and mental health, and stress-related factors [8,9].

Because rehabilitation is the cornerstone of treatment in cerebral palsy, the parents' cooperation with the rehabilitation team is very important. Their cooperation can be affected by their psychological, physical, and social status. Several studies have evaluated the QOL of parents of children with CP and found it to be worse than parents of healthy children [10-16]. There are some reports evaluating the QOL of parents of CP patients and there is need for further studies in this regard in the Middle East. In this study we aim to investigate the quality of life of the parents of children with CP in comparison to parents of healthy children and its correlations with possible risk factors in the northwest of Iran.

Material and Method

In this cross-sectional study, we evaluated the quality of life of 64 parents of children with CP and 64 parents of healthy children who were referred to rehabilitation clinics of Tabriz University of Medical Sciences, Tabriz, Iran. Inclusion criteria were parents of children with confirmed CP without any other neurological or orthopedic problems of their child and no history of psychiatric or physical disorder in the parents. Parents with healthy children were selected from the families of relatives or neighbors with healthy children. Parents were excluded if they refused to participate in the study. Parents of more than one child affected by CP were not included in the study. The ethics committee of Tabriz University of Medical Sciences approved the study. All participants gave written informed consent.

Families were visited by researchers to administer questionnaires to parents. Self-report questionnaires were used to collect data on all study variables. Data collection was performed using the World Health Organization Quality of Life – short version (WHOQOL-BREF) and the Duke University Religion Index (DUREL) questionnaires for the parents and the evaluation of the motor skills of the children according to the Gross Motor Function Classification System (GMFCS) by a physiatrist with more than 10 years of professional experience.

WHOQOL-BREF Questionnaire

The WHOQOL-BREF questionnaire consists of 26 questions in four domains of physical, psychological, social, and environment health. The Persian version of the questionnaire used in this study has been previously approved for reliability and validity [17]. Scores for each domain were transformed to a common 0–100 scale.

DUREL

The Duke University Religion Index (DUREL) consists of three subscales: organizational religious activity (ORA), non-organizational religious activity (NORA), and intrinsic religiosity (IR). It has a total score of 5 to 27, with lower scores indicating weaker religious beliefs. We used the validated Persian version of the DUREL (FDUREL) in this study [18].

GMFCS

GMFCS (Gross Motor Function Classification System) is a standard observational tool for assessing children with cerebral palsy. It evaluates the ability to perform movements such as walking, climbing stairs, running, and sitting. According to this scale, children are placed into five grades from I to V according to their gross motor skills. Lower levels represent better gross motor skills, with I as the least severe and V as the most severe level [19].

Statistical Analysis

All statistical tests were performed using the Statistical Package for Social Science for Windows (SPSS) version 17.0. Results are expressed as mean ± SD or percentage. In comparison of parameters, Student's ☒- and chi-square or Fisher's exact tests, as appropriate, were used to compare data between groups of patients. Pearson correlation was used to evaluate the correlation between variables. The result of the Kolmogorov-Smirnov test with p-value of 0.235 indicated normal distribution of the quality of life data. A p value of <0.05 was considered statistically significant.

Results

In this study, QOL of parents of 64 children with CP was compared with QOL of parents of 64 healthy children. The demographic data of the two groups are presented in Table 1. There was no significant difference between groups regarding the baseline data. Cerebral palsy types were quadriplegic in 17 (13.3%), diplegic in 19 (14.8%), hemiplegic in 17 (13.3%), ath-

Table 1. Demographic data of parents of cerebral palsy and healthy children

		Cerebral Palsy	Healthy	P value
Age				
Parents		35.48±8.01	33.57±6.48	0.14
Children		6.35±3.62	6.00±2.82	0.53
Gender				
Parents	Male	16 (25%)	23 (35.9%)	0.24
	Female	48 (75%)	41 (64.1%)	
Children	Male	35 (54.7%)	33 (51.6%)	0.72
	Female	29 (45.3%)	31 (48.4%)	
Marital status	Married	62 (96.9%)	62 (96.9%)	-----
	Divorced	2 (3.1%)	2 (3.1%)	

etoid in 7 (5.5%), hypotone in 3 (2.3%), and ataxic in 1 (0.8%) of the cases.

According to GMFCS, CP children were in level I in 10 cases (7.8%), level II in 7 cases (5.5%), level III in 12 cases (9.4%), level IV in 17 cases (13.3%), and level V in 18 cases (14.1%).

Table 2 shows the comparative QOL data of quality of life of parents of children with CP and parents of healthy children. Compared to the parents of healthy children, parents of children with CP had a lower score in all subscales of the QOL and in the overall score. The difference was significant in overall QOL and all its domains, except for the social subscale. Comparing the mothers of both groups and the fathers of both groups separately, there were significant differences for maternal quality of life but not for paternal quality of life. There was also no significant difference between gender (mothers and fathers) within each group.

Using the DUREL questionnaire, we observed that parents of children with CP had stronger religious beliefs than the healthy group (21.58±4.12 vs. 18.36±5.73; p<0.001).

The correlations between quality of life subscales and age, DUREL score, and GMFCS were evaluated (Table 3). There was significantly negative correlation between parents' age and psychological domain, social domain, and overall QOL. Overall QOL and its subscales, except for the social subscale, were positively correlated with the parents' DUREL score, but none of these subscales had a significant correlation with the religious beliefs of parents. We also observed significantly negative correlations between GMFCS level and the social and environmental health domains.

Parents of children with CP were asked to define their income as "enough" or "less than enough"; the responses numbered 18 and 46, respectively. Families with enough income had significantly higher scores in social, environmental health, and overall quality of life (Table 4).

Parents of children with CP had education of fewer than 8 years in 33 cases and more than 8 years in 31 cases. Comparing the QOL domains, only environmental health was significantly higher in parents with higher education (Table 5).

Table 2. Comparison of quality of life of parents of both cerebral palsy and healthy children

	Cerebral Palsy	Healthy	P value
Physical domain	49.4±13.1	55.5±10.2	0.004*
Mothers	49.06±14.21	54.71±9.74	0.03*
Fathers	50.56±9.63	57.09±11.27	0.06
Psychological domain	52.33±15.10	57.82±12.41	0.02*
Mothers	51.31±16.12	57.71±12.20	0.04*
Fathers	55.56±11.31	58.22±13.24	0.51
Social domain	60.6±20.6	65.2±21.05	0.2
Mothers	62.90±20.69	67.85±22.46	0.28
Fathers	54.06±19.69	60.52±17.73	0.29
Environmental Health	52.1±15.8	59.09±15.9	0.01*
Mothers	52.63±16.74	60.73±14.58	0.01
Fathers	50.81±13.19	56.17±18.17	0.32
Overall quality of life	53.6±12.9	59.4±11.2	0.008*
Mothers	53.97±13.94	60.25±10.93	0.02*
Fathers	52.75±9.81	58.00±11.99	0.15

* P is two sided significant. Data are presented as Mean ± SD.

Discussion

Parents of children with CP are required to provide care to their child both day and night and so there is less time for parents to attend to their own needs. In this study, we evaluated the QOL of parents of children with CP compared to parents of healthy subjects. We observed that parents of children with CP have lower scores in all domains of the WHOQOL-BREF questionnaire, except for the social domain, compared to parents of healthy children. We observed similar results for maternal quality of life, but the difference in parental quality of life between groups was not significant.

The literature has few studies that have assessed the QOL of parents of children with CP [10-16]. Similar to our study, Guillamón et al. [13] observed that the parents of children with CP had lower levels of QOL than the general population. In a study by Okurowska-Zawada et al. [15], the QOL of parents of children with CP was lower in all four subscales than in the parents of healthy children, especially in the psychological and environmental health subscales. Terra et al. [20] also showed that parents of children with CP had a lower level of QOL in comparison with a control group.

Regarding the QOL of parents, we observed no significant difference between mothers and fathers within each group and between fathers of both groups, while mothers of children with

Table 3. Pearson correlations between parents age, DUREL score, and GMFCS level with domains of quality of life

Correlations	Pearson correlation	P value
Parents age with		
Physical domain	-0.033	0.793
Psychological domain	-0.274	0.02*
Social domain	-0.387	0.002*
Environmental Health	-0.237	0.059
Overall quality of life	-0.315	0.01*
DUREL score with		
Physical domain	0.216	0.08
Psychological domain	0.071	0.57
Social domain	-0.086	0.49
Environmental Health	0.103	0.41
Overall quality of life	0.073	0.56
GMFCS with		
Physical domain	-0.109	0.39
Psychological domain	-0.059	0.64
Social domain	-0.267	0.03*
Environmental Health	-0.281	0.02*
Overall quality of life	-0.237	0.06

* p is two sided significant.

Table 4. Correlation between quality of life and level of family income in cerebral palsy group

	Less than enough	Enough	P value
Physical domain	48.30±14.10	52.10±10.09	0.3
Psychological domain	51.20±16.00	55.30±12.40	0.3
Social domain	57.50±20.10	68.80±20.30	0.04*
Environmental Health	49.40±15.30	59.20±15.20	0.02*
Overall quality of life	51.60±13.07	58.80±11.40	0.04*

* P is two sided significant. Data are presented as Mean ± SD.

CP had significantly lower QOL than mothers of healthy children. Other studies have reported similar results when evaluating the QOL of mothers of children with CP [14-16, 21-23]. Similar to our findings, Davis et al. [10] found no differences in parental QOL among mothers and fathers. However, Byrne et al. [5] found that mothers had worse mental and physical health compared to fathers.

The stress and the burden on the family is the cause of low QOL in these parents. It is suggested that taking care of children with CP affects the physical and social well-being, the independence, and the financial stability of their caregivers [10].

We also found a negative correlation between GMFCS level and the social and environmental domains, showing that with increase in the severity of the disability, parents have more problems in these domains. These two domains include items such as satisfaction with the financial situation, entertainment, access to convenient transportation, and health services.

It is reported that severe disability in children is correlated with parental stress, which could be a cause for lower QOL [24]. However, studies regarding the quality of skills reported conflicting results. Two studies reported a significant correlation between the QOL of parents and the degree of their child's disability according to GMFCS [16,25,26]. However, other studies have found that the child's level of disability does not affect QOL of the mothers [10,12,16,27].

Many parents use religion and faith as a method of coping, and spirituality has been shown to be a source of strength and purpose for both the family members of disabled people and persons with disabilities [28]. Perhaps religious beliefs can help people tolerate difficulties in these situations. We evaluated the possible correlation between religious beliefs and QOL and observed that parents of children with CP had stronger religious beliefs but lower QOL than the healthy group. The overall QOL and its subscales, except for the social subscale, had a positive correlation with parental DUREL score, but none of these subscales had a significant correlation with the religious beliefs of parents. Considering these result, we did not find any proof regarding the effect of religious beliefs on QOL of parents of children with CP.

We also observed that scores for overall QOL and its subscales decreased with increasing age; in other words, older parents experienced lower QOL. Previous studies have shown that as maternal age increases, QOL decreases [29]. It is suggested that an increase in age may be associated with depression, which could negatively affect QOL [29]. However, Davis et al. [10] did not find any difference in parental QOL among different age groups.

We evaluated the correlation between family income and parents' education with the QOL domains and found significant correlation between family income level and parental QOL in social, environmental health, and overall quality of life and between educational levels with the environmental health domain. Khayatzadeh et al. [21] also observed that the socioeconomic status is associated with all domains of QOL in mothers of children with CP. Similarly, Ones et al. [27] found negative correlations between education status and QOL. Unlike our findings, Yilmaz and colleagues [26] found no association between QOL of mothers and their educational status or level of income.

Brehaut et al. [3] reported that most of the parents of children with CP are less involved in full-time jobs and have lower incomes because caring for their families is their main activity. Tekinarslan et al. [29] observed that with increase in family income, QOL is improved. Previous studies have suggested that low income is the causes of stress and mental health disorders in parents of children with CP. It seems that having financial support and better education could improve the QOL of these parents [30]. However, Ribeiro and colleagues [16] did not find any relation between family income and parental stress.

Study limitations

There were some limitations for the current study. First, the sample size is small, which may affect the strength of the results. Furthermore, our sample of fathers was small. It is suggested to recruit a higher sample size in future studies, including the same number of mothers and fathers. In addition, most of the measures used in this study are parent-reported, and some findings may be overstated. Another limitation was use of a self-report data collection tool.

Conclusion

In conclusion, parents of children with CP have lower quality of life (QOL) than parents of healthy children. QOL is negatively correlated with children's disability level, parental age and education, and family income. Although these parents had stronger religious beliefs, this was not correlated with the domains of quality of life.

Competing interests

The authors declare that they have no competing interests.

References

1. Hadders-Algra M. Early diagnosis and early intervention in cerebral palsy. Front Neurol 2014;5:185.
2. Berker N, Yalçın S. The HELP guide to Cerebral Palsy. 2nd ed. Washington, USA: Global Help-Merrill Corporation. 2010.p.7-131.
3. Brehaut JC, Kohen DE, Raina P, Walter SD, Russell DJ, Swinton M, et al. The health of primary caregivers of children with cerebral palsy: how does it compare with that of other Canadian caregivers? Pediatrics 2004;114:e182-91.
4. Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, et al. The health and well-being of caregivers of children with cerebral palsy. Pediatrics 2005;115:e626-36.
5. Byrne MB, Hurley DA, Daly L, Cunningham CG. Health status of caregivers of children with cerebral palsy. Child Care Health Dev 2010;36:696-702.
6. Parkes J, Caravale B, Marcelli M, Franco F, Colver A. Parenting stress and children with cerebral palsy: A European cross-sectional survey. Dev Med Child Neurol 2011;53:815–21.
7. Majnemer A, Shevell M, Law M, Poulin C, Rosenbaum P. Reliability in the ratings of quality of life between parents and their children of school age with cerebral palsy. Qual Life Res 2008;17:1163-71.
8. Davis E, Mackinnon A, Waters E. Parent proxy-reported quality of life for children with cerebral palsy: Is it related to parental psychosocial distress? Child Care Health Dev 2012;38:553-60.
9. Smith AM, Grzywacz JG. Health and well-being in midlife parents of children with special health needs. Fam Syst Health 2014;32:303-12.
10. Davis E, Shelly A, Waters E, Boyd R, Cook K, Davern M, Reddihough D. The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. Child Care Health Dev. 2010;36:63-73.
11. Strom H, Kreuter M, Rosberg S. Quality of life in parents/caretakers of children with cerebral palsy in Kampong Cham, Cambodia. J Trop Pediatr 2012;58:303-6.
12. Prudente CO, Barbosa MA, Porto CC. Relation between quality of life of mothers of children with cerebral palsy and the children's motor functioning, after ten months of rehabilitation. Rev Lat Am Enfermagem 2010;18:149-55.
13. Guillamón N, Nieto R, Pousada M, Redolar D, Muñoz E, Hernández E, et al. (Quality of life and mental health among parents of children with cerebral palsy: the influence of self-efficacy and coping strategies. J Clin Nurs 2013;22:1579-90.
14. Dehghan L, Dalvand H, Feizi A, Samadi SA, Hosseini SA. Quality of life in mothers of children with cerebral palsy: The role of children's gross motor function. J

Child Health Care 2016;20:17-26.
15. Okurowska-Zawada B, Kulak W, Wojtkowsku J, Sienkiewicz D, Paszko-Patej G. Quality of life of parents of children with cerebral palsy. Prog Health Sci 2011;1:116–23.
16. Ribeiro MF, Sousa AL, Vandenberghe L, Porto CC. Parental stress in mothers of children and adolescents with cerebral palsy. Rev Lat Am Enfermagem 2014;22:440-7.
17. Nedjat S, Montazeri A, Holakouie K, Mohammad K, Majdzadeh R. Psychometric properties of the Iranian interview-administered version of the World Health Organization's Quality of Life Questionnaire (WHOQOL-BREF): a population-based study. BMC Health Serv Res 2008;8: 61.
18. Hafizi S, Memari AH, Pakrah M, Mohebi F, Saghazadeh A, Koenig HG. The Duke University Religion Index (DUREL): validation and reliability of the Farsi version. Psychol Rep 2013;112:151–9.
19. Russell DJ, Avery LM, Rosenbaum PL, Raina PS, Walter SD, Palisano RJ. Improved scaling of the gross motor function measure for children with cerebral palsy: evidence of reliability and validity. Phys Ther 2000;80:873-85.
20. Terra VC, Cysneiros RM, Schwartzman JS, Teixeira MCT, Arida RM, Cavalheiro EA, et al. Mothers of children with cerebral palsy with or without epilepsy: a quality of life perspective. Disabil Rehabil 2011;33:384-8.
21. Khayatzadeh MM, Rostami HR, Amirsalari S, Karimloo M. Investigation of quality of life in mothers of children withcerebral palsy in Iran: association with socioeconomic status, marital satisfaction and fatigue. Disabil Rehabil 2013;35:803-8.
22. Bella GP, Garcia MC, Spadari-Bratfisch RC. Salivary cortisol, stress, and health in primary caregivers (mothers) of children with cerebral palsy. Psychoneuroendocrinology 2011;36:834-42.
23. Hamzat TK, Mordi EL. Impact of caring for children with cerebral palsy on the general health of their caregivers in an African community. Int J Rehabil Res 2007;30:191-4.
24. Al-Gamal E, Long T. Psychological distress and perceived support among Jordanian parents living with a child with cerebral palsy: a cross-sectional study. Scand J Caring Sci 2013;27:624-31.
25. Eker L, Tazan EH. An evaluation of quality of life of mothers of children with cerebral palsy. Disabil Rehabil 2004;26:1354-9.
26. Yilmaz H, Erkin G, Ali İzki A. Quality of Life in Mothers of Children with Cerebral Palsy. ISRN Rehabilitation 2013;2013:914738.
27. Ones K, Yilmaz E, Cetinkaya B, Caglar N. Assessment of the quality of life of mothers of children with cerebral palsy (primary caregivers). Neurorehabilitation and Neural Repair 2005; 19:232-7.
28. Poston DJ, Turnbull AP. Role of spirituality and religion in family quality of life for families of children with disabilities. Education and Training in Developmental Disabilities 2004;39:95-108.
29. Tekinarslan IC. A comparison study of depression and quality of life in Turkish mothers of children with Down syndrome, cerebral palsy, and autism spectrum disorder. Psychol Rep 2013;112:266-87.
30. Sipal RF, Schuengel C, Voorman JM, Van Eck M, Becher JG. Course of behaviour problems of children with cerebral palsy: the role of parental stress and support. Child Care Health Dev 2010;36:74–84.

How to cite this article:
Shirmard MH, Seyyedi M, Toopchizadeh V, Ghojazadeh M. Low Quality of Life and its Associated Risk Factors in Parents of Children with Cerebral Palsy in the Northwest of Iran; A Case Control Study. J Clin Anal Med 2017;8(5): 431-5.